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ABSTRACT

This newsletter issue provides stories of leaders who have developmental disabilities, descriptions of program initiatives and models promoting leadership opportunities for individuals who are disabled, and an historical overview of leadership issues. Major articles include: "Leadership: Where We've Been, Where We Are, Where We're Going" (Hank Bersani, Jr.); "Leadership by Persons with Disabilities: Perceptions, Needs, and Opportunities" (Brian Abery and Michael N. Sharpe); "The Impact of Gender and Race on Leadership by Persons with Disabilities" (Jacquelyn Anderson Bolden); "Real Leaders Ask Questions, Real Leaders Make People Understand" (Michelle Hoffman); "Building a Network of Leaders" (Jill Flynn); "Civic Leadership: Youth in Government" (Polly Harrison); "A School for Community Leaders" (Carolyn Lejuste); "Culturally Diverse Leadership: A Model of Inclusion" (Betty Horton); "Learning To Lead...Leading To Learn" (Michael N. Sharpe); "Students in Community Leadership" (Julie Schreifels); "Leading by Serving: Maryland Student Service Alliance" (Cathy L. Brill); "Empowerment through Leadership Education" (Stephanie Agresta et al.); and "Remembering with Dignity: Leadership through Activism" (Jerry Smith). Annotations are provided for 10 resource publications. (SW)

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IMPACT

INSTITUTE ON COMMUNITY INTEGRATION
COLLEGE OF EDUCATION AND HUMAN DEVELOPMENT
UNIVERSITY OF MINNESOTA

Feature Issue on Leadership by Persons with Disabilities **Volume 8 (3) Summer 1995**

For 25 years, Barb Eaton lived in a state institution. Today, she is working with other self-advocates to tell the stories and preserve the memory of all who've lived in Minnesota institutions. See story below and on page 24.

Making Things Better: Barb's Story

by Walter Rupp

Barb Eaton doesn't consider herself a leader. "I'm a doer. I just like to get things done and make things better." In the late 1980s, Barb worked tirelessly to cut through bureaucratic red tape and gather information about the 25 years she lived in a Minnesota state institution. With the help of others, her efforts resulted in a video documentary called *The Lost Years*, which chronicles her life before, during, and after living in the state institution. It is an incredible story of Barb's personal growth and her relationship with her family and community. Barb says she told her story for personal reasons. "My work to tell my story in *The Lost Years* video was a healing process for me. It helped me understand myself better and to get closer to my family." Barb often talks about how the process of telling her story led to a great many new friends and pushed her to do things she had never done before. "I challenged myself to do things I didn't know I could do and I proved to myself and others that I could do it."

Barb has been involved with self-advocacy groups in the past, but only marginally. She says that she has often found self-advocacy meetings frustrating because things often didn't seem to get done. But recently, Barb got involved with a group of self-advocates and others working to place names on the numbered or unmarked graves of Minnesotans buried in state institution cemeteries and to tell the stories of people who have lived in Minnesota's state institutions. The project is

Eaton, continued on page 27

From the Editors

Most persons do not view themselves as leaders. This is in part because of the images of a "leader" that are offered us. Leaders, for example, are often viewed as charismatic individuals who inspire others to action through fiery speeches. Leaders are also often thought of as unusually attractive, intelligent, powerful, talented, and/or prosperous. Still others think of leaders as martyrs who sacrifice all for a cause. While there are leaders who have these traits, we believe that there are other ways of looking at leadership that make it an option for all persons, not just the exceptional few.

Among those who benefit from a re-examination of the concept of leadership are persons with developmental disabilities. Many people have assumed that leadership and disability are incompatible. Yet, in spite of exclusionary definitions of leadership, individuals with developmental disabilities have in fact been filling many leadership roles, especially in the disability rights movement. They have, intentionally and unintentionally, debunked the myth that people with disabilities cannot lead.

In this *IMPACT* are the stories of some of those individuals. Readers will also find models for organizations, schools, businesses, and agencies to follow in embracing a more inclusive vision of leadership, and creating opportunities for more people with disabilities to develop and exercise their capacity for leading.

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A publication of the Institute on Community Integration (UAP) and the Research and Training Center on Residential Services and Community Living, College of Education and Human Development, University of Minnesota. Dedicated to improving community services and social supports for persons with disabilities and their families.

Leadership: Where We've Been, Where We Are, Where We're Going

by Hank Bersani, Jr.

What does it take to be a leader? What makes a movement? Who are the present and former leaders in the developmental disabilities movement? What will come next? In the past, these were relatively straightforward questions with fairly clear, direct answers. Today, however, the responses are more complex because many more voices are being heard, most significantly the formerly silenced voices of people with disabilities. Leadership in the disabilities movement has emerged where we never expected it a few decades ago: from individuals with developmental disabilities. They represent the latest of three stages, or "waves" as I call them, in the evolution of the movement to date.

■ The First Wave: Professionals

Not long ago, the field of developmental disabilities was more of a professional discipline than a rights movement, although many in the discipline were in fact interested in the rights of people with developmental disabilities. Among these professionals, leaders were people with academic credentials who held positions in the related fields of medicine, psychology, education, and special education. From as early as 1850 to as recently as 1950, the list of leaders in the field that we now call *developmental disability* were famous professionals who had developed test procedures, reached clinical insights, and started new programs. Books on what we called *mental retardation* featured the "early leaders" such as Itard, and Seguin and Howe, physicians in the 1800s.

Leaders in the field often functioned within organizations. Until the 1950s, the oldest and largest organization in the field was the American Association on Mental Deficiency (AAMD). For over 100 years, AAMD was an association of professionals, by professionals, for professionals, and the assumptions of the time were clear: Professionals know what is best, people with disabilities are defined by their disabilities (mental deficiency), and skilled researchers and scientists will lead the way to better services, therapy, and reduced disability. I have called this stage of leadership development "The First Wave."

In those days, at the height of The First Wave, professionals, as leaders, defined the issues and created the new discipline of developmental disability separate from the fields of medicine, psychology, and education. They made decisions on their own or in consultation with each other. The activities of these leaders included forming state and national organizations, convening national conferences, publishing research articles and books on disability, issuing position statements, and consulting to programs locally, nationally, and even internationally.

During The First Wave, people with developmental disabilities were often seen as less than human. To most professionals, they were "subjects" in experiments and the objects of studies. In the United States at this time there was a growing emphasis on the role of science in our lives. Therefore, the goal of the disabilities field was to apply science to achieve better understanding of causes and possible cures of the "deficiency." Consequently, people with "mental deficiency" were viewed as having nothing to contribute to the field beyond their role as subjects of research. In addition, as the science around disabilities evolved, it focused increasingly on prevention – immunizations, testing for problems such as PKU, and so forth. In the context of a focus on the science of prevention, there was little use for the people who represented failures of prevention efforts.

■ The Second Wave: Parents

In the late 1940s and early 1950s, there was a dramatic development: the Parents Movement. After World War II, the United States experienced a new prosperity. People had more leisure time and more income. This meant that they were able to turn their attention to issues other than economic survival. Concurrently, the baby boom was taking place, which meant that not only were more babies being born, but also more babies were born with developmental disabilities. As a result of this combination of factors, parents of children with disabilities, especially mental retardation and cerebral palsy, began to form their own support and advocacy groups. This was "The Second Wave."

At first, the goal of these organizations was simply for parents of children with disabilities to support one another. Later, as the organizations matured, parents also began to advocate for themselves, their children, and each other. In order to win the respect of the professionals in the field, they became more organized, although at the time no one called it a "movement." As parents of children with disabilities sought each other out, they formed local and state organizations, and a national organization that was at first known as the National Association for Retarded Children (NARC).

The Parents Movement had a profound effect on the developmental disability field. Parents acknowledged that there was a role for professional expertise, but they pointed out that they knew their family members better than any professional ever would. As parents, they had a lot to say about their family members, especially their young children. They demanded that parents be included when professionals met to

discuss the needs of children with disabilities.

Many parents joined the professional organizations, including AAMD. At one point there was a suggestion to make the emerging parent organization, NARC, a part of AAMD. The president of AAMR, Mildred Thompson, had the good sense to say that the best way that AAMD could support the Parents Movement was to assist them in developing their own organization. At the height of The Second Wave, NARC's membership far exceeded that of AAMD. Several other parent organizations formed as well. Parents had established themselves as leaders. They joined professional organizations, formed their own organizations, established newsletters and journals focusing on parent issues, published in professional texts and journals, shaped the language of the field, and redirected the emphasis at conferences.

■ The Third Wave: Self-Advocates

In the early 1970s, something remarkable happened in the field of developmental disabilities. The 1950s and 1960s had been a time of new advocacy groups forming on a range of issues across the country. From Ralph Nader's consumer advocacy, to the civil rights movement, to the women's movement people were claiming greater power, control, rights, and freedom for themselves and others. People with developmental disabilities, the same people whom the professionals and even the parents had called "clients" and "the retarded", also began to organize with the help of staff and other allies. What emerged as "The Third Wave" of the developmental disabilities movement has become known as the Self-Advocacy Movement.

Self-advocates have organized partly in reaction to the attitudes promoted by professionals and parents, and also in part to copy those groups' methods as effective approaches to advocacy. In the past 25 years, self-advocates have formed their own organizations at local, state, and national levels, so that today there are over 600 self-advocacy groups across the country. Self-advocates have organized conferences to discuss issues that are most important to them, joined the long-established professional and parent organizations such as AAMD and the Arc, published their own newsletters, published articles in journals and newsletters of parent and professional organizations, given major addresses at professional and parent conferences, published chapters in books, and changed the language of the field to "people-first." A major milestone in this Third Wave has been the establishment of the national organization, Self Advocates Becoming Empowered. To the leaders in the movement, the formation of the group was a major step in achieving a national presence.

Many self-advocates have identified their own significant indicators of success. As a long-time supporter and observer, several individuals and events stand out for me:

- Valerie Schaaf was one of the founders of People First International 25 years ago. She went from living in an institution to being a national leader in the Self-Advocacy Movement, and is generally credited with originating the phrase, "see people with disabilities as people first."
- Barbara Goode, a leader of the Self-Advocacy Movement in Canada and internationally, recently was selected to give an address to the General Assembly of the United Nations.
- Michael Kennedy, a self-advocacy leader from New York state, testified before the U.S. Senate on his years growing up in an institution. His leadership has inspired many others to become self-advocates.
- The People First group in Tennessee made history by being the first self-advocacy group to bring a lawsuit against the state to close an institution.
- In Colorado, self-advocates, including Debbie Allen, lead the fight to have people with disabilities included on the boards of directors of service agencies.

For most self-advocates (and for me) the greatest measure of success is how they have affected the rest of us, the professionals and parents. They have changed our organizations, the names of our organizations, our attitudes, our language, our practices, and have caused us to redefine our issues. They have brought us slogans such as "Nothing about me without me." And they have made us nervous.

Making people nervous is an indicator of success. If a would-be social movement has only a few members and no power, they do not make us nervous. We become concerned when the group becomes big enough and organized enough to be an effective movement. That causes a reaction from those who want things to remain unchanged. We wonder, "Will they go too far? Can they go too far? What will be our role if they become the leaders? What part of my expertise is still useful or wanted?" When The Second Wave emerged, professionals were reluctant to give up any of their power to parents. Today, many parents and parent organizations, in addition to professionals, are also reluctant to give up their power and influence to self-advocates. But, there is no changing the inevitable: We cannot and should not discuss developmental disabilities without the participation of the individuals with disabilities themselves. In this Third Wave, the leaders in the developmental disabilities movement are the self-advocates. And the biggest sign of their success as leaders is that they make the rest of us – professionals and parents – nervous.

Hank Bersani, Jr., is Director of Special Education with the Oregon Health Sciences University, Portland. He may be reached at (503) 494-3696. Many of the concepts presented here are discussed in a new book by Gunnar Dybwad and Hank Bersani entitled New Voices: Self-Advocacy by Persons with Disabilities *published by Brookline Books.*

Leadership by Persons with Disabilities: Perceptions, Needs, and Opportunities

by Brian Abery and Michael N. Sharpe

If one defines leadership in the manner in which it is typically viewed in our society – such as Martin Luther King's ability to inspire a great social movement through the use of extraordinary oratory skills – then it is a foregone conclusion that there will always be a shortage of effective leaders. This is not, however, the only manner in which one can view leadership. A broader perspective is that *all* persons inherently have the potential to lead.

The belief that the capacity for leadership is present within all individuals is based upon two fundamental assumptions. The first focuses upon the idea that although each person may use a unique leadership "style" and be faced with a different set of leadership challenges, *everyone* has the potential to learn and apply leadership skills. Some persons may lead through using their organizational abilities. The leadership of others may emerge as a result of their capacity to assist groups in reaching consensus. Still others may have the gift of oral or written persuasion. Regardless of the specific skills they employ, each of these persons is carrying out a leadership function.

... although each person may use a unique leadership "style" and be faced with a different set of leadership challenges, everyone has the potential to learn and apply leadership skills.

The second assumption underlying the belief that all persons have the potential to effectively lead transcends the typical notion of leadership as based upon the efforts of a single individual; it redefines the construct from an empowerment perspective. Viewed from this position, an effective leader is not necessarily a person who possesses all of the skills and capacities necessary to facilitate a group reaching its goals, but rather is an individual who effectively empowers others to use the capacities they possess to their fullest potential in an effort to promote individual and group goals. Given this broader perspective, leadership may be thought of as a collection of interpersonal skills and values that enable an individual to facilitate group achievement of the following: (a) developing and reaching consensus with respect to a vision, mission, and set of goals; (b) deciding on a course of action; (c) working in an effective manner to reach its goals; and (d) enhancing the self-actualization, empowerment, and self-determination of its members. This definition is quite different from traditional perspectives on leadership.

Viewed through this lens, effective leaders are not necessarily people who have a vision and, through great skills of persuasion, convince others to follow them. Rather, leaders are persons who are effective at facilitating groups of individuals collaboratively deciding what they want to do and how this can best be accomplished. It is unlikely that many persons will possess all of the skills and characteristics necessary to facilitate these tasks. This does not mean that such individuals are not good leaders. Effective leaders are aware of their capacities as well as their limitations, and are willing and able to drawn upon leadership abilities of other group members to help achieve common goals.

In addition to the belief that leadership can be expressed in many different ways, it is also proposed that opportunities for leadership exist in everyday life and that it is only a matter of degree and one's own personal circumstances that determine the extent to which leadership skills are applied. Parents, for example, exhibit leadership when they help other family members decide upon a course of action. Children display leadership when they suggest modification of the rules of a game so that all present have the opportunity to play. These would not necessarily be viewed as instances of leadership using traditional definitions of the construct. Upon close examination, however, it can be seen that, in each of the above examples, actions were taken that facilitated a group of individuals achieving a goal.

The importance of identifying and facilitating the distinctive qualities of leadership is neither purely academic nor insignificant for persons with disabilities. Many of the significant changes within educational and social service delivery systems that have enhanced the quality of life of persons with disabilities have been initiated by such individuals themselves. Whether at the local, state, or federal level, the work of individuals with disabilities functioning in leadership capacities has been critical to the passage and enforcement of disability rights legislation, changes in the manner in which residential services are provided, and increased opportunities for meaningful participation in the workforce. The Americans with Disabilities Act and the Individuals with Disabilities Education Act, for example, would in all likelihood have never been passed without the leadership skills of persons within the disability community. The formation and growth of consumer advocacy groups would have been impossible in the absence of the leadership provided by many self-advocates. It was persons with disabilities who served as the catalysts behind deinstitutionalization and the creation of less restrictive community residential and employment programs.

There exists today a critical need for skilled, informed persons with disabilities to serve as advocates for other individuals with disabilities and to stimulate systems change. Unfortunately, there is only a limited pool of persons with disabilities who have had the opportunity to fully develop their leadership skills. Many of these persons have spent countless hours organizing within the community, testifying in legislative bodies, and educating the general public about disability-related issues. Presently, however, there are simply not enough of these individuals to take on all leadership functions. As a result, discussion and action related to issues needing attention must often be postponed.

The efforts of individuals with disabilities who have served as leaders have contributed enormously to enhancements in the quality of services available to this group, as well as to their increased inclusion within the community. Because leadership is typically considered to be an attribute possessed primarily by "the gifted and talented," however, persons with disabilities have, for the most part, been excluded from participation in leadership development programs and have had few opportunities to assume positions of leadership within communities. Similar to the experiences of persons of color, women, and those from disadvantaged circumstances, members of this diverse group have been viewed as lacking the potential to function effectively as leaders. When persons with disabilities do receive the opportunity to practice and refine their leadership capacities, it is typically within the context of preparing them to function as leaders of "the disabled" rather than within society at large.

Over the past decade, persons with disabilities such as Judith Heumann, T.J. Monroe, Nancy Ward, and the late Ed Roberts have assumed positions of leadership in a variety of organizations serving children and adults with disabilities. The efforts of these individuals have done much, at the societal level, to improve the quality of life experienced by persons with disabilities and to dispel the belief that such individuals are not capable of functioning as effective leaders. The majority of individuals with disabilities who have become effective leaders, however, have done so in spite of, rather than as a result of, the manner in which they were treated within society.

The positive impact of the leadership of persons with disabilities is not limited to a few individuals whose efforts have stimulated change at the societal level. The ongoing efforts of persons with disabilities who do not even consider themselves to be leaders have brought about changes that have resulted in an enhanced quality of daily life for both themselves and others. The experiences of Jim, Susan, and Kevin bear this out. Jim, a 36-year-old man who has spent the majority of his adult life working in a sheltered workshop, recently was successful in convincing those who operate the program to install large fans to make the work environment more comfortable during the summer months. His success was largely due to his persistence, belief in the validity of his cause, and ability to organize all 16 of his coworkers in support of this change. Although the air conditioning that he and his coworkers would prefer has yet to be installed, Jim's efforts have led to a considerably more comfortable work setting for himself and his peers.

Susan is a 45-year-old woman who currently resides in a six-person community residence operated by a respected service provider. Although she has few complaints about her accommodations, Susan recently initiated an effort to pressure her service provider to drop the name "children" from the agency title since the organization currently serves only adults with developmental disabilities. Although this effort may appear trivial to some, to Susan and her peers it represents an attempt to "make sure that the persons who work with us recognize that we are adults just like them."

As one of the first students within his school district to receive his education primarily within inclusive settings, Kevin led by example for a number of years, demonstrating to fellow students, parents, and professionals that persons with developmental disabilities cannot only survive but are able to thrive within general education settings. The leadership this young man exercises, however, goes far beyond his merely serving as a role model. Since his high school years, Kevin has spoken at local, state, and national levels to fellow students, parents of children with disabilities, and professionals about his experiences within inclusive education settings.

Enhancing the quality of life of persons with developmental disabilities is a long-term effort. It is an effort that, if it is to be successful, must receive its direction not from professionals or parents, but from persons with disabilities themselves. The identification of policies and regulations that need to be changed, problems that must be addressed, and programs that are important to develop can be best accomplished through extensive input and leadership on the part of those individuals most affected. Until persons with disabilities are supported to lead and provide direction with respect to these efforts, attempts to achieve the goal of full inclusion within the community will remain less than adequate.

Currently, there are many obstacles to individuals with disabilities assuming leadership roles. Among the most powerful of these barriers are those that are attitudinal in nature. Myths and misconceptions about the capabilities of persons with disabilities remain entrenched within our society, reinforced by a service system that appears more interested in focusing on what individuals cannot do as opposed to their capacities and potential. Attempts to question authority are referred to as "challenging behavior," efforts to stimulate change viewed as irritants, and compliance deemed an acceptable program outcome toward which to aspire. In addition to external attitudinal barriers, many individuals with disabilities do not view themselves as having the capacity to lead, in part because the current system under which they receive services functions to effectively socialize many of them into dependent roles. Until this cycle is broken and persons with disabilities begin to envision

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The Impact of Gender and Race on Leadership by Persons with Disabilities

by Jacquelyn Anderson Bolden

Much has been written about leadership, both formally in the social science and management fields and informally in popular publications. For too long leadership has been conceptualized narrowly as a special form of power and influence. When constructed in this way, many people become exempt from leadership roles because they are not viewed as having the requisite capacities to do the job. In the United States, many individuals – on the basis of their race or ethnicity, gender, and/or disability – also experience restricted access to leadership roles as a result of individual and institutional discrimination. In spite of changes in our social structures, workforce, and legal system, leadership roles continue to be narrowly distributed.

Three themes emerge in the general literature about leadership that are relevant to the discussion of leadership on the part of people with developmental disabilities. The first is that leadership need not be narrowly distributed; leadership possibilities exist across gender, racial, class, and other boundaries. The second theme is that leadership roles are fluid, not static. And the third is that people are not born leaders, but develop leadership skills. These three themes will be explored here in an effort to develop strategies for encouraging leadership that facilitates the self-actualization, empowerment, and self-determination of individuals with disabilities.

■ Who is an Appropriate Leader?

Opportunities to develop the capacity, gain the experience, and obtain the opportunities to lead are influenced by society's perceptions of individual and group appropriateness for leadership roles. Leadership and the male role within American society have traditionally been seen as congruent, while leadership and the female role have often been thought of as incongruent. Several factors are responsible for this. One is that womens' rewards have traditionally not been located in the leadership arena, but in the realm of caring for others. Further, because women are socialized to hold non-leadership roles, societal expectations function to diminish their motivation for leadership. Contemporary options for paid employment have significantly affected role expansion for women, and women leaders are becoming more visible. Assumptions about the *appropriateness* of female leadership, however, are still of central importance to consider in discussions about limits on women's opportunities.

The legacy of exclusion of Native Americans, African Americans, Asian Americans, Latinos and other racial/ethnic groups from participation in mainstream American life continues to have an impact upon opportunities for achieving leadership positions in many organizations and professions. It can be argued that legal and social barriers can be held responsible for the underdevelopment of leadership capacity among individuals in different racial/ethnic groups. Segregation, however, did not preclude the development of leadership skills within racial/ethnic communities. Notable contemporary leaders like Jewel McCabe, Eleanor Holmes, Dorothy Height, Jesse Jackson, and Andrew Young held important and visible leadership positions in African American communities during periods when de jure and de facto segregation precluded their involvement in these roles within mainstream organizations. Today, while formal legal barriers have been lifted, racial discrimination continues and resistance to include racial/ethnic people in mainstream leadership roles persists. Assumptions about their capacity to lead in wider society are the primary stereotypes to be challenged for racial/ethnic people.

The exclusion of persons with disabilities from mainstream society has served to marginalize and limit them, as well. Persons with disabilities are perceived as perpetual children and are therefore not socialized to occupy key roles in society. The focus on what people with disabilities are *unable* to do has significantly affected the perception of what they are *able* to do. Assumptions that limit the possibility of leadership must be addressed if persons with developmental disabilities are to experience role expansion.

The experience of exclusion from leadership roles that are valued by society as a whole is intensified for individuals who are members of more than one excluded population. When considering leadership by persons with disabilities, it is important to recognize that they may not only be dealing with biases – internal and external – based on perceptions about disability, but if they are female and/or members of minority racial/ethnic communities, there are additional biases and barriers to overcome.

■ What Do Leaders Do?

Leadership is contextual. Therefore, what is expected of a leader is dependent upon the setting and the needs of the group. Formal leadership roles typically include solving problems, planning for group action, directing activities, communicating effectively, understanding and developing oneself, accessing resources, understanding financial matters, being creative, managing meetings, and arbitrating. A leader is not someone who possesses leadership traits. Leadership, like any other role behavior, is a function of dynamic interaction between personal attributes and the social system.

Leadership is distributed in varying amounts among group members most able to meet group needs. As needs change, leadership distribution within the group changes.

Leadership skills are acquired through formal and informal processes. The development of competencies for leadership include the opportunity to practice and use knowledge and skills. Organizational and community initiatives have evolved to provide models for the development of leadership competencies among many who have been formerly excluded. Self-advocacy projects, for example, have emerged to teach persons with developmental disabilities strategies for problem-solving, identifying resources, and posing key questions to obtain important information. Preparing an agenda, conducting a meeting, and encouraging group members to work in committees are among other skills taught. The diversity of skills that need to be taught depends largely upon the organization or group in which they will be utilized. Generating a list of what one needs to know or do to be effective in an organization or group is a strategy for delineating which competencies may need to be developed.

While the potential for developing leadership skills exists in settings where women and racial/ethnic persons with disabilities receive services and participate in programs, such individuals are often excluded. One explanation may be institutional discrimination. The maintenance of racial, gender, and ability hierarchies occurs because services and programs for persons with disabilities mirror those in the wider society. These all tend to be hierarchical. Administrators and staff consciously and unconsciously reproduce situations and structures with which they are familiar and comfortable. For example, when white male directors identify leadership opportunities for persons with disabilities, often women and minorities are not initially considered. In instances when women and minorities are selected for leadership opportunities, sufficient supports that would facilitate their success in novel roles may be absent.

■ Leadership Development: A Case Study

The following case study is provided to illustrate how one African American woman with a disability *was* provided with opportunities to develop leadership skills and was supported until her transition to leadership roles occurred. Deana* is a woman with a developmental disability who has been involved in a mutual help and self-advocacy organization. She resides in a group home, but would like to occupy a supervised apartment in the city. Prior to the group home, she had lived most of her life in a large residential facility. When she initially became involved with the self-advocacy organization, she was extremely shy and, because of past experiences with racial discrimination, expressed concern about being the only African American in the group. Over time, she began to feel safe and trusting of fellow members. Consistent attendance and participation in the meetings and social events of the organization formed the basis of her initial steps toward leadership skill acquisition. Taking responsibility for herself was critical to assuming other responsibilities. After attending organizational meetings for more than a year, Deana had developed a network of friends within the group. This network provided support, urged self-acceptance, and encouraged her to attempt more activities. As Deana became more confident, she began to reach out to others as well. Participation in formal leadership within the organization began to evolve with her willingness to take responsibility for reminding others to attend group meetings with phone calls. Later, she selected records for a dance, planned a menu for a picnic, and initiated action to acquire recreational materials for the group. After being involved in the organization for more than five years, she led a group to the state capital to speak to elected officials about legislation.

Deana's story points toward the possibilities of leadership acquisition through the process of building competencies and providing meaningful opportunities to learn new skills and take on new challenges. It also points to the multiple issues that need to be addressed when gender and racial barriers have reinforced the marginalization experiences of disability. Deana's self-esteem issues were complicated by her negative experiences of racial exclusion; her willingness to get involved in the organization was compromised by her distrust of the group. Her hesitancy to try many roles was complicated by her ideas about what women are able to do; she volunteered to do gender-stereotyped tasks (like menu planning) before she was willing to assume responsibilities that were more gender neutral or "male like."

■ Conclusion

How can service providers and advocacy groups avoid stereotyping individuals with disabilities on the basis of gender and racial/ethnic identity? First, those in positions of responsibility or authority can routinely ask themselves, "Have I given everyone a chance to try a leadership role? If not, why not? Do I limit the kinds of tasks I ask women and minorities to do? Have I encouraged women and minorities who are in new leadership roles, and offered support so that they are more likely to succeed?" Secondly, service providers and advocacy groups can develop strategies to assure that inclusion occurs. A buddy system that pairs a new leader with a more seasoned one is one way to use mentoring to support those new to leadership roles. Formal training opportunities can also be provided, incorporating role playing and situational practice. The possibilities for leadership development are limitless. Creative problem-solving and a desire for change are the primary components required to make it happen for *all* persons with disabilities.

Jacquelyn Anderson Bolden is Visiting Assistant Professor with the School of Social Work, University of Iowa, Iowa City. She may be reached at (319) 335-1264.

* Pseudonym

Real Leaders Ask Questions, Real Leaders Make People Understand

by Michelle Hoffman

It happened again. Rob, who was promoted last fall from direct care staff to program coordinator, was fired because he couldn't fulfill his role as coordinator. He sure was great at direct care, though. And just the other day, Lisa, who was a case manager and took the job as executive director of an employment agency, resigned because she didn't want the responsibilities of being a director.

Again, we are reminded that leadership is an art. It is something to be learned and nurtured over time. Building and fine-tuning leadership skills is a process for us all. Real leadership does not happen overnight. It does not come with a label or a position. Personal experiences, personal drive, and opportunities to learn and grow as leaders give us the materials needed to build and develop our skills.

Many members had been placed on boards and committees and were eager to serve. However, members did not feel involved, supported or important to the group process and were therefore stuck in a role without direction.

In the realm of consumer leadership, a surge of leaders has been emerging as a result of the self-advocacy movement. Years of organizing and developing leadership skills have paid-off as the movement produces some of the finest leaders in the disability field. The very people who were once locked out of leadership roles, given meaningless board and committee positions, and often (still) told to "be quiet and let us take care of things" are taking their rightful places as leaders. Through the self-advocacy movement, much discussion, writing, and teaching is occurring regarding consumer leadership. Several state groups, such as People First of Tennessee, People First of Washington, Speaking for Ourselves, and Oklahoma People First have produced materials and training about consumer leadership.

One such training program, Leadership Plus, was developed by Oklahoma People First members who identified the need for basic leadership skill training during a statewide self-advocacy conference. Many members had been placed on boards and committees and were eager to serve. However, they often did not feel involved, supported or important to the group process and were therefore stuck in roles without direction. Leadership Plus was created to help alleviate this predicament by assisting more people with developmental disabilities to acquire the basic leadership skills necessary to serve as consumer representatives on boards and committees.

Leadership Plus focuses on how and why leadership skills are developed, responsibilities as consumer representatives, why boards and committees exist, and the meeting process. Other components of the training relate to communication, and making group and personal decisions. The training takes approximately eight hours to complete, and is conducted in a classroom-type setting using discussion, role playing, group games, and small group activities. Leadership Plus is designed to be led by anyone with leadership experience, including consumers who have previously participated in a trainee capacity. In addition, past participants are often asked to serve as support persons for new participants.

Since the training began in 1992, 60 people have participated in the Leadership Plus program in Oklahoma and the majority are actively serving on boards and committees. Pre- and post-program evaluations indicate that participants have gained increased knowledge about meeting processes, consumer representation, and how to become a board or committee member. In addition to training in Oklahoma, the program is being presented in over 35 states, Mexico, and Australia. In some instances, local self-advocacy groups, residential providers, and others present the Leadership Plus materials, and on other occasions Oklahoma People First staff travel to other states to conduct training.

Throughout the Leadership Plus training one theme remains constant: If you don't understand something, ask questions until you do understand. And if people don't understand you, keep talking until they do.

A side piece to the training is *I Make A Motion Too....*, a pamphlet designed to assist board and committee members in supporting consumer representation. The publication discusses the need for consumer participation on boards and committees, especially those that serve people with disabilities. It has been requested by groups around the country, and users indicate that it helps them make the case for the participation of people with disabilities.

Throughout Leadership Plus training one theme remains constant: If you don't understand something, ask questions until you do understand. And if people don't understand you, keep talking until they do. Real leaders ask questions. Real leaders make sure people understand them.

Michelle Hoffman is Self-Advocacy Coordinator for the Tulsa ARC, and serves as the advisor to Oklahoma People First, a program sponsored by Tulsa ARC. For further information about Leadership Plus training or materials, contact Michelle at (918) 582-8272. Leadership Plus is funded by the Oklahoma Planning Council for Developmental Disabilities.

Being a Leader: Leon Barrett

My name is Leon Barrett. I live in Tulsa, Oklahoma. I have some things that I would like to tell you about my experiences in being a leader.

I first learned about being a leader in People First. I really wanted to do it, to be a leader. But, I didn't really know how. I started out by being secretary in our local group. Now I'm vice-president. But, it took time to get here. I also serve on the Tulsa ARC board of directors and as a member of a human rights committee. All of this has taught me a lot. I am proud that I am able to help people by being on these things.

I took the first Leadership Plus training and it was fun. In that training, I learned that I can do it, I can be a leader. And I learned that if you don't understand something, then it's your responsibility to ask questions until you do understand. I try to do that. Sometimes it's hard because people have a hard time listening to my questions. Sometimes I am too shy to ask and I think that people will think my question is stupid. That's hard. I'm still learning about that.

A person who is a leader is serious about what they are doing as a leader. I am serious. A leader also respects people, listens to people, and looks people in the eye.

When I lived in institutions, I did not have a chance to be a leader because the staff did everything. I have learned a lot from my friends Joe and James. They have taught me that I can be a leader, be active, and make a difference. Watching others has helped me learn to be a good leader.

If I could give advice about helping people be on committees, I would say:

- Help people understand what the committee is for. It is frustrating when you don't know why you are there.
- Explain things in easy language. I get confused when people talk way above my head, especially with the budget.
- Summarize information. Don't give anyone a bunch of stuff to read because people don't.
- Make sure people are supported. James helps me on the ARC board. It's good to have someone that you know you can turn to.
- Stop the meeting if you don't understand. Sometimes I am too afraid to ask. Leaders should ask questions like, "Does everyone understand?" Sometimes groups have so much to talk about that they don't want to stop. When that happens it tells me that they really don't care if I understand or not.
- If you say you are going to explain something to someone after the meeting, then do it.

That's all I have to say about being a leader.

Leon Barrett is a self-advocate and vice president of People First, Tulsa, Oklahoma.

Building a Network of Leaders

by Jill Flynn

Leadership can be a hard word to truly understand. It means many different things to people. I tend to agree with Napoleon Bonaparte: "A leader is a dealer in hope." Leadership is based on a vision or dream supported by a group of people who work together to reach it. Leaders can see others' abilities and get them actively involved. A leader helps others become better leaders by working with them, listening to them, and acting on their hopes and visions.

The Oregon Developmental Disabilities Council has often worked with self-advocates who desire to be strong leaders, providing opportunities to go to trainings and speak at public hearings, task forces or panel presentations on self-advocacy. This has helped individuals to grow as leaders, but several years ago the council also saw the need to provide more opportunities for these leaders to make their own connections and work together.

The initiative supports the building of a viable network of individuals with disabilities who are interested in being active as leaders on the state level.

In 1992, staff from the DD Council and one of its projects, Community Partnerships, met with People First of Oregon board members and advisors to discuss self-advocacy in Oregon. People First members described barriers to leadership that existed in the community and the supports they would need to overcome those barriers. Members raised issues such as communication with other self-advocates, transportation, and getting and keeping advisors and support people. The idea of a self-advocacy initiative developed out of these discussions and the DD Council's desire to support broader networking and collaboration by self-advocates exercising leadership.

In 1994, an initiative was written, presented to, and passed by the People First of Oregon board, and supported by the DD Council. The initiative supports the building of a viable network of individuals with disabilities who are interested in being active as leaders on the state level. To help achieve that goal, the council and Community Partnerships offered to work with People First to support three areas of activity: support and strengthen existing People First chapters, develop new chapters, and expand the political influence of self-advocates in Oregon.

The initiative provides a small amount of money to support the work. To make the most of limited dollars, Community Partnerships pays salaries and the DD Council adds in-kind support with materials and staff support. Two part-time staff people each work 30 hours per month on the initiative: Judy Cunio, one of the original founders of People First of Oregon, and Michael Bailey, an active community organizer and the parent of a child with a disability. They strengthen existing chapters by offering advice, ideas, and other assistance related to needs such as finding advisors, arranging transportation, running a group, working together, finding support people, and fundraising. They support new chapters by coordinating assistance and personal visits from existing chapters. And they encourage expanded political influence of self-advocates by working with Community Partnerships staff to adapt existing advocacy training materials and write them in easy-to-understand language. In addition, they support the involvement of interested self-advocates in monitoring their own services, in voter registration drives, and in building advocacy teams in communities to educate policymakers about issues and help them change their attitudes. They also respond to phone calls on a toll-free number, maintain an updated listing of self-advocates in Oregon, and gather information on how other states' self-advocacy groups work.

This past March, a planning meeting was held to identify additional steps to be taken by the initiative. People First members were very clear about what they wanted: training and education for social service agencies, direct-care staff, and employers about self-advocacy; leadership training for the state and local boards; help to format and mail a newsletter; advisor training and support; assistance in strengthening communication between members; and resource materials on running meetings, community organizing, fundraising, and team-building. They also requested aid in identifying training that is available for self-advocates in skills such as listening, assertiveness, mediation, and negotiation. Initiative staff are currently seeking individuals who have skills in these areas to assist with trainings so that self-advocates can become better leaders and involve others in their communities.

The intended outcome of the initiative is a team of strong leaders within the People First movement...

The intended outcome of the initiative is to develop a team of strong leaders within the People First movement who can work with other teams in Oregon, be active partners in policymaking and legislative efforts, and help convince the people of Oregon of the contributions people with disabilities can make. The DD Council and Community Partnerships will continue to support People First of Oregon

in strengthening existing chapters, establishing new chapters, and expanding the political influence of people who have disabilities as we work to realize our common vision of independence and dignity for self-advocates in communities around the state, nation, and world.

Jill Flynn is the Self-Advocacy Coordinator with the Community Partnerships Project, Oregon Developmental Disabilities Council, Salem. For further information on the Oregon self-advocacy initiative contact Judy Cunio or Michael Bailey at (503) 945-9229.

Judy Cunio: What Makes a Good Leader?

Over the past 21 years, I have developed leadership skills through a lot of practice in various roles. It takes time to find out what works and what does not work, how you relate to people and how they relate to you. Being a good leader has a lot to do with your attitude and why you have taken on that role.

A leader has to care about the people they are leading and believe in the things they are doing. There needs to be a commitment. A leader will follow through; if they say they will do something, they will do it. That is one way a leader needs to be an example to other people. The person who is a leader needs to be confident and motivated. One of the big differences between leaders and anyone else is that a leader must be able to delegate, to get people involved. If you do all the work, others don't get involved. Leaders are outspoken and they need to have confidence to know that they are able to lead. This does not mean that they should take over, but they keep people on track.

Now that I have said so much about what a leader is, why do I call myself a leader? I hope that I am a good example, that I live what I say. I want people to see that when I say something, I mean it, that I am not a hypocrite. I hope that I encourage people to do things themselves. I think I am pretty assertive and try to be direct when I communicate. At the same time, I hope that I am sensitive to how other people feel and motivate people to share their ideas. I try to give them a chance to give their opinions and say "yes" or "no."

As many leaders have in the past, I have faced challenges in my role as a leader. The biggest of these is communication because I am hard to understand. Even if it is hard for people to understand me, I still have to be able to get my message out. I have trouble doing that because sometimes people don't take me seriously. At those times I try not to get frustrated because that only makes it worse. I think my speech is hard to understand. I try to get help from people I know will understand to communicate my ideas. I also have a Realvoice computer (that I call Mabel) which helps me to present speeches.

Working with Oregon's self-advocacy initiative gives me an opportunity to do something I know I can do. Community Partnerships staff give me the supports I need to carry out my responsibilities and they treat me like a colleague. That's important; it gives me more confidence in myself. I hope the work I do will help make People First strong and make the organization better, not only for me, but for all of the people who are involved. It will empower people to continue to grow and develop their skills and do what they want.

If that happens, my job will not be necessary. So what do I see myself doing in the future? I want to be a writer who has the ability to impact people. I have proven to be the strongest as a leader when I write. When I write, I have a greater impact on people, I can make them think and better understand. I plan to continue my writing to bring up issues that people need to know about and understand. I like to make people think.

Judy Cunio is one of the founders of People First in Oregon, and is currently a staff member of the Oregon self-advocacy initiative. The above photo was taken during legislative training at the State Capitol, during which Judy (with hand raised) sparked discussion among other self-advocates by sharing her experiences in talking with legislators.

Civic Leadership: *Youth in Government*

by Polly Harrison

Minnesota offers many experiential opportunities for adolescents to develop civic leadership skills, but none are as large or as inclusive as the Minnesota YMCA Youth in Government Model Assembly Program. Under the direction of former State Representative Peter Rodosovich, over 1000 eighth through twelfth graders annually perform roles in the mock executive, legislative, and judicial branches of state government. The program encourages life-long, responsible citizenship by providing experiential learning for young people interested in public issues, and providing forums for recognition of the abilities and capabilities of youth.

The program encourages life-long, responsible citizenship by providing experiential learning for young people who are interested in public issues...

Over the past four years since youth with developmental disabilities have begun participating in the program, 38 have been involved, with 11 students with developmental disabilities participating in 1995. Most of these students have gotten their start toward the Model Assembly Program through the YMCA's inclusive Leadership for Empowerment (L.E.P.) Program. The L.E.P program is a service-oriented leadership program involving junior high/middle school youth with and without disabilities throughout the state. Participants develop an appreciation for individual strengths and how to work together to serve the broader community. The program also sponsors an inclusive leadership camp each summer and serves as a resource for YMCAs and other youth development organizations working toward full inclusion. The L.E.P. program was the catalyst for establishment of the inclusive Model Assembly program and continues to coordinate support for youth with developmental disabilities during their participation by coordinating transportation and securing interpreters and personal care attendants.

The Model Assembly program begins each September with the formation of delegations at YMCAs and high schools around the state. The participants register for a particular program area – Senate, House of Representatives, Court of Appeals, Supreme Court, Cabinet, news media, and lobbying – and then the work begins at the delegation level. Depending upon their program area and role, delegates engage in a variety of activities. For participants who aspire to run for office, there are speeches to write and campaign strategies to develop. Those filling the roles of senators, representatives, and lobbyists determine positions on issues and express them through authoring bills and position papers. Media correspondents attend training to learn how to write news stories and operate broadcast equipment. Delegations rely on local resources and adult professionals to help them with their work.

In October, the State Convention is held (a replication of a party convention) in which delegates elect their governor, lieutenant governor, chief justice of the Supreme Court, chief judge of the Appeals Court, secretary of state, attorney general, president of the Senate, and speaker of the House for the upcoming Model Assembly session. The annual culmination of the program is the four-day Model Assembly session held at the State Capitol in January. During the session, delegates have the opportunity to act as senators and representatives, governor and lieutenant governor, attorneys and judges, legislative pages, lobbyists, and press corps. It begins with the swearing in of officers, which is close-circuit broadcast to all program areas. The program areas then get to the business at-hand, which includes committee meetings for the House and Senate, arguing cases in the Court of Appeals and Supreme Court, and meetings for the media correspondents to determine coverage and assignments. While some pages are busy running messages for the legislators, others learn about the three branches of state government through an educational series running throughout the session.

The presence of youth with disabilities has benefited not only those youth, but has also contributed to this learning experience for others by demonstrating that leaders evolve from every part of our diverse society.

The only adaptation made so far to the structure of the Model Assembly program for participants with disabilities is to have each participant with a disability register with a nondisabled peer as a team. The two are usually friends or peers from the same school. They work together throughout the program, whether it be authoring an article for the newspaper or following bills as members of the Governor's Cabinet. While there is currently no formal training specifically related to supporting a partner who has a disability, teams have functioned well because most members have known each other from the L.E.P. program and worked together previously. If problems or questions arise, staff are available to provide information and assistance.

During the 1995 Model Assembly, there were two teams in the Cabinet and Humphrey House, four teams that worked as pages, one team in the Court of Appeals, and two teams in the press corps. One of our proudest moments came when three of our page teams at the page mock convention had a candidate on the final ballot for speaker of the House, president of the Senate, and the governor ticket. Additional highlights included the Court of Appeals team earning a decision in their favor – the only appellate team to do so on that particular case – and three of the Cabinet members being interviewed for the final edition of The Capitolist, the Model Assembly's daily newspaper.

Opportunities such as the Model Assembly program have a far reaching impact on all the youth who participate. They develop stronger leadership skills, expressing their views with confidence and conviction, learning to work as team members, and listening to and respecting one another. They take these skills back to their schools and exercise them in their L.E.P. groups and other activities. The presence of youth with disabilities has benefited not only those youth, but has also contributed to this learning experience for others by demonstrating that leaders evolve from every part of our diverse society.

Polly Harrison is a Youth Development Specialist with the YMCA of Metropolitan Minneapolis, Ridgedale Branch. She is the director of the statewide Leadership for Empowerment Program and coordinated the inclusive efforts of the 1995 Model Assembly. For additional information on the Youth in Government Model Assembly Program, contact Polly at (612) 544-7708.

Experiencing Leadership in Government: Mark Terauds

My name is Mark. This was my second year in the Youth in Government program. Both years I have been a member of the Governor's Cabinet. A cabinet member follows bills through the legislative process. I had to fill out forms and report to the rest of the cabinet on how the bills were doing. Being in Youth in Government helps me understand my government classes at school better, and it's a more fun way to learn.

The first year I was a little nervous because I was worried about making a mistake. But, this year I knew what to expect. My confidence was stronger and I could start doing my job before someone asked me to. Some people who were on the cabinet this year did it last year, too, and I remembered them.

Besides being in the cabinet, there was lots to do that weekend. We all stayed in a hotel and at night they had activities for us. I liked singing karaoke and sang *Puff the Magic Dragon* twice, once as a solo and once with a group. The D.J. gave me some cool sunglasses for doing a good job. The cabinet went on a tour of the house of James J. Hill (founder of the Great Northern Railroad) and we met with the governor's press secretary.

As a leader in the Youth in Government program, I had to work hard and let people know how the youth governor felt about bills. I think leaders have to work hard and have to like to help people. Sometimes people don't want your help, though, and you have to listen to them. A leader also has to be willing to take risks sometimes, like when you have to stand up and talk or sing in front of people. I liked being in Youth in Government because it made me work hard. I met lots of people and had fun, too.

I'm a leader at school, too. I'm an actor in the group Y's Act, and we just put on a play about violence in the media. Soon, I'll be working, but even through I'm busy I want to go to Youth in Government again next year.

Mark Terauds is a high school junior and lives in the Minneapolis suburb of Eden Prairie.

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A School for Community Leaders

by Carolyn Lejuste

At the Leadership Development School for People with Disabilities (LDS) we believe that – given an opportunity, some resources, and a little support – people with disabilities can identify and solve their own problems. Through the process of identifying a community issue they wish to address and working with others to influence the issue, participants in the program acquire leadership skills and develop their own unique leadership styles. As they attend six weekend training events held over a nine-month period, participants grow in their ability to be in charge of their own lives and the disability rights movement, and return to their communities as self-confident and determined leaders.

The LDS program is driven by the self-identified needs of participants. Individuals attend in teams of four, and with the assistance of a LDS staff coach each team identifies an issue around which they develop a project in their home community. Team projects are structured around a Participatory Research model as defined by Peter Park in the book *Voices of Change*. Participatory Research teaches people to identify questions related to an issue, seek information through research methods that stand up to academic rigor, and create a strategy for use of the information to advocate for change. It is an opportunity for people who have been the objects of research to assume an active role in uncovering knowledge that is important to their lives. In the process, teams connect with others who are interested or involved in the issue and enlist assistance in solving the problem, which builds group capacity. Team members develop skills in communication, assume responsibility for follow-through, and learn to trust one another.

Program activities and participant behavior are guided by three values identified by the first year's class: respect, inclusion, and responsibility. One challenge to upholding these values while meeting individual participant needs and pursuing a goal is that the needs of participants are sometimes contradictory because they have various kinds of disabling characteristics – cognitive, emotional, and physical. As they work together, participants develop ways to accommodate one another and also examine biases or assumptions about people with different disabilities. For instance, individuals with speech characteristics need additional time to be understood. Consciousness-raising occurs as their peers take the time to listen to them and examine commonly-held assumptions of cognitive disability in persons with speech difficulties. Concurrently, participants become aware of assumptions regarding people with cognitive disabilities. Accomplishing tasks while involving and respecting everyone encourages the development of relationships in which all are noticed and appreciated for what they offer.

Another challenge in LDS is that people with disabilities have often been socialized to be dependent on other people or on the system that supports them. The environment within LDS demands that participants take responsibility and action in their lives. Moving away from dependency has implications for change in the behavior of professionals, family members, and people with disabilities alike. For professionals and families, the challenge is to understand and accept that things will be different when people with disabilities are in charge of their own lives, choices, decisions, and rights movement. And for people with disabilities, the challenge is to recognize and change habits of dependence.

Because participants have often been discouraged from practicing their leadership skills within their home communities, LDS has designed the program to increase the opportunity for direct support. By accepting teams, the program encourages the development of peer supports that hopefully will continue after attending LDS. In addition, a coach is assigned to each team to listen to and support individuals, ask questions to help clarify project goals and tasks, and organize the design of the training based on the needs identified by the participants. The coaches, some of whom were participants in the first year's class, are people with disabilities who are working hard to understand ways of developing new leaders and put that knowledge into practice.

The impact of the LDS approach can be seen in the projects that teams are carrying out, and the manner in which team members are working together. For example, a team from Kalamazoo is researching models of screening and training personal assistants. In the process, they have noticed problems in communicating with one another. They are now also researching and practicing different ways of listening to each other and giving feedback. A team from a local People First group is researching transportation issues. They are concerned about bus delays and are tracking the number of times that their own buses are late. They are also looking at who is really in charge of transportation money and decisions, and have written letters to the governor to express their concerns. And a group from the Upper Penninsula is working to establish an advocacy organization, and is in the process of organizing an event that will bring together other people with disabilities who may be interested. These and the other team projects demonstrate the truth of the belief underlying the LDS approach: given an opportunity, resources, and support, people with disabilities can solve their own problems.

Carolyn Lejuste is the Administrator of the Leadership Development School for People with Disabilities. She may be reached at (517) 487-1755. The school is a three-year project of Michigan Protection and Advocacy Service in Lansing, funded by the W.K. Kellogg Foundation.

Crossing Barriers: Kelly Watson

A leader is responsible. A leader is someone who sees a need in the community and has the commitment to take it on. But, he/she recognizes that the issue cannot be handled by one person. A leader has to have the ability to get other people involved in the issue and be willing to delegate responsibility to get things accomplished.

Recognizing leaders is sometimes confusing. There are people who do not see themselves as leaders. They take on a problem/issue and just do it. Other people who call themselves leaders want personal recognition and try to take all the credit for getting something done.

One of the ways that I'm a leader is that I care about and understand what's happening in the disability community; I see the injustices, oppression, mistreatment and abuse that I and other people with disabilities receive from society. Another way I see myself as a leader is that I always try to think of the group's needs first. I try my best to accommodate other people's needs, yet keep them focused and moving forward. If I know there is a communication problem within the group, I make the individuals deal with it. I try my best to listen before making a judgment or telling people what to do.

One barrier to becoming a leader, as always, is the attitudes that society has about people with disabilities. The nondisabled community has a lot of preconceived notions about the disability community. That makes it hard to deal with an issue. A good example is my speech characteristic (or my CP accent as I prefer to call it). When I get involved in a project and the people don't know me, they often patronize me because I can't speak as clearly as they would like. They assume that because of my speech I don't know what I'm talking about.

Another type of barrier is paternalism. Because the nondisabled community is so used to taking care of people with disabilities, it's hard for them to give us the opportunity to make our own decisions. There are two issues here. One is they are afraid we can't think for ourselves, and therefore we will make the wrong decisions. The other is that it has been their job for so long to decide what's best for us that they have trouble relating to us as equals.

Political savvy is another challenge that I face as a leader. What I mean by this is that you have to know when to be strong and take a risk by stepping forward, making your views known. A lot of times these views are new to the group and they may be opposing views. People like this about me; it is one of my strengths. It also encourages people to try to get me to take on the role of spokesperson for different organizations. Before taking the role on, I have to think about things I'm already involved in. I have to question whether it will hinder any of the other projects I'm involved in, and ask if it's going to build my own network/coalition. As a leader I have had to learn to say "no" in order to remain effective in my chosen projects.

One way in which LDS assisted me is that it provided me with networking experiences. I met people from around Michigan. This helped me a great deal because it allowed me to share my ideas with them and get people's feedback on my projects. Also, by attending LDS weekends I learned about different techniques of communication within groups. I learned that my techniques of communication and my ideas about how to achieve goals were not so atypical. This was very affirming to me as a leader. Another support I received from LDS was that people were there to listen to my concerns, problems, and issues regarding leadership. This is very important because some people outside of the advocacy realm cannot relate to what advocates experience.

One of my future interests is to get insurance funding for service animals. Service animals offer a great deal of independence to people. They are a form of assistive technology service that is not paid for yet by public or private insurance. Those of us who rely on service animals have to rely on the good hearts of other people to buy our service animals.

I would like to continue to talk about LDS on the national level. My goal is to help spread the word about the LDS model to other states. I would like to be involved either in bringing students from other states to our school in Michigan, or in designing regional LDS programs in other parts of the U.S.

Kelly is one of the Leadership Development School (LDS) team coaches and also was a member of the first year's class. She has cerebral palsy and is dependent on technology, including her service dog, to live independently. Her project at LDS was to get service dogs and personal assistant services included in the definition of Michigan's Assistive Technology project (AT). Her efforts led AT and Michigan Protection and Advocacy Service to include service dogs in their case priorities.

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Culturally Diverse Leadership: A Model of Inclusion

by Betty Horton

Sweeping reforms are occurring in the disability field. The consensus, by professionals and persons with disabilities alike, is that the old system does not work. Radical changes are occurring at all levels – from public policy, to services, to person-to-person interactions. The reforms seek to accomplish two goals: full integration of people with developmental disabilities into public life, including schools, the workplace, and the community; and the extension of all the rights and responsibilities of citizenship to a group of people to whom they have historically been denied. By far, the more fundamental reforms have to do with changing the status of persons with disabilities from outcasts to full citizens. This status change is reflected in terms such as "self-determination," "empowerment," and "leadership."

Reform initiatives aimed at full inclusion and citizenship move us closer to fulfilling the promise of civil rights for people with developmental disabilities that began on the heels of Brown v. Topeka Board of Education in 1954. Ironically, the one group that remains, "the most locked out and left behind" are culturally diverse people with disabilities (Williams, 1994 p. 52). The reasons for the exclusion of African American, Hispanic/Latino, Native American, and Asian American people with developmental disabilities from leadership roles in and as a result of reform initiatives are many. More important than the reasons, however, are the actions taken to correct the situation.

■ A Vision for Inclusive Practices

The beginning point of every reform initiative is to create a vision of what is desired. One example of vision statements for inclusionary practices in relation to culturally diverse persons with disabilities can be found in the following statements that guide the activities and gauge the progress of the Inclusive Practices for Culturally Diverse Persons program at the University of Kansas:

- **Vision 1**. Culturally diverse persons with disabilities, their families, and culturally diverse professionals are fully represented as key planners, organizers, speakers, and participants at every conference and meeting.
- **Vision 2**. Culturally diverse persons with disabilities and their families, and culturally diverse professionals are fully represented on advisory boards, planning committees, and in executive positions of key agencies and organizations.
- **Vision 3**. Culturally diverse persons with disabilities and their families, and culturally diverse professionals are fully represented in key leadership roles in universities, service agencies, and in organizations.
- **Vision 4**. Culturally diverse persons with disabilities and their families, and culturally diverse professionals are satisfied with the range of options and opportunities for participation and leadership in university, service agencies, and organizational settings.

These vision statements reflect the program's belief that the leadership of culturally diverse persons with disabilities represents a vast, untapped resource. Persons with disabilities must be given opportunities to become strong enough to participate within, share control of, and have an influence on events and institutions affecting their lives. We believe that our job is to help young persons with disabilities help themselves and others. For these reasons, the goal of the program is to provide opportunities for culturally diverse persons with disabilities to "show and grow" their leadership skills.

■ A Process for Inclusive Practices

After the vision statements were developed, the next question was: Where should we begin? In Kansas, we began with a statewide conference called Building Community Supports for Culturally Diverse Young Adults with Disabilities and Families: Strategies for Inclusion. Twenty-eight young adults and their family members from Caucasian, African American, Hispanic/Latino, Native American, and Asian American backgrounds participated in planning the conference, and presented sessions on such topics as housing and independence, communicating with service professionals, and employment barriers. Additionally, the families and young adults each invited an influential person (e.g., school superintendent, agency director, mayor) to become their exclusive partner for a day at the conference. The purpose of the conference was to help set the stage for young persons with disabilities, families, and influential leaders to become partners in reforming services and delivery systems. During the conference, the young adults and their families were recognized as the experts, and their views of services and service delivery issues were sought by the policymakers and professionals. In particular, the role of the young adults was to lead the discussion by sharing their perspectives, providing information, and advocating for themselves and others.

Feedback from participants has indicated that the conference was a success in several ways. First, many participants reported that it debunked myths and misconceptions they had held about each other; instead of concentrating on disability or racial labels, participants got to know each other personally. Secondly, the professionals and policymakers became newly aware of a cadre of potential leaders who are culturally diverse and have disabilities. Thirdly, a sense of community and mutual respect was generated among

participants; many, particularly those who were partnered with each other, have continued to keep in touch. And lastly, young adults and their families had an opportunity to become "insiders" as a result of the exposure and visibility given them in their leadership role; for instance, several of the young people have been invited to become board members of non-profit or state agency councils.

■ Conclusion

This conference began with the premise that professionals and others can take certain steps to set the stage for leadership by culturally diverse persons with disabilities and their families. As we continue to follow the vision of full inclusion of all citizens with developmental disabilities, the challenge will be to resist the tendency to be satisfied with just a little progress. Every university, agency, and organization must pull together until people with disabilities from African American, Hispanic/Latino, Native American, and Asian backgrounds are fully represented as participants and leaders in every aspect of the current reforms.

Betty T. Horton is an Assistant Research Professor at the Kansas University Affiliated Program (UAP)/Lawrence and is the Chair of the Work Group on Cultural Diversity. The Inclusive Practices for Culturally Diverse Persons program is a collaborative effort of the Kansas UAP, Kansas Council on Developmental Disabilities, Kansas Protection and Advocacy Services, Cerebral Palsy Research Foundation of Kansas, Kansas Department of Social and Rehabilitation Services, and other agencies and organizations. For further information contact Betty at (913) 864-4950.

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Leadership and Ambition: Askia F. Adams

Hello, I'm Ski, and I want to share with you what I would like and how my team of people (my brother, mom and dad, school advisors and others) have been trying to help me get those things I want. I don't consider myself a leader. I enjoy the challenge of working toward a goal. I like trying to prove others wrong. Like in debate; I used augmentative communication using the laptop computer and synthesized speech. The teacher said that I helped him learn to accept people that are somewhat different.

I am physically challenged and have a speech impediment. I can do things other students can do, but it takes me longer. I want to become a special education teacher in elementary school. Several years back I wanted to be a computer programmer, and would still like to get a degree as a backup in computer programming.

To get to my goals, I decided in middle school I wanted to go to college. I realize it might take me awhile to get through college. I also told my parents then that I did not want to live at home after graduating from high school. My plans are to go to college, get a job, and have my own apartment or home.

My parents, school teachers, vocational rehabilitation counselors, and an agency called WDDS are helping me work toward my goals. The school has provided me with speech, occupational and physical therapy, assistive technology, and vocational counseling. My vocational counselor at school has helped me to evaluate my strengths and weaknesses as well as look realistically at my future needs. My 10th grade year I had a pullout class called Career Decision Making, a mini-course where your values and interest are assessed. Ms. McBeath also helped me look into taking a class at a vocational school in microcomputers, but I decided I'd rather take classes that would help me get ready for college. WDDS has helped me after school by providing a personal attendant who helps me until my parents get home or goes with me on outings for social things. I'm on their waiting list for independent living referrals when they become available and I'm ready to move away from home.

I don't really know what will happen after college, but I hope there will be an agency out there that will help me get a job, a job coach, housing, and other support to live my life as an average person.

Askia F. Adams is a 17-year-old senior at F.L. Schlage High School in Kansas City, Kansas. He has maintained a 4.0 average grade point in high school, is ranked first in the entering senior class at Schlage, and hopes to be considered for valedictorian. One of his hopes is to be able to stand and walk at the graduation ceremony.

Learning to Lead... Leading to Learn

by Michael N. Sharpe

Within the past decade, one of the fastest growing curriculum options that has become available to secondary school students in the United States is the opportunity to enroll in courses that help to define one's role as a socially responsible member of society. Typically, such courses are designed so that students are given the chance to participate in cooperative learning and team building activities, but it is intended that these skills will ultimately have broader application in addressing social issues.

Once predominately the role of social and religious organizations, educational institutions have recognized the need to move beyond traditional curricular paradigms to promote learning opportunities aimed at enhancing personal growth and development within the context of social consciousness. Whether the focus of instruction involves service learning, peer mediation, or activities involving collaborative teams, a factor essential to each is the concept of leadership.

As a discipline, the study of leadership has undergone a rather dramatic change, from an early trait model that suggested that leadership skills were reserved for a few, to a more contemporary view that focuses on personal empowerment and development of skills that are within the grasp of virtually everyone. The curriculum developed for the Learning to Lead...Leading to Learn project exemplifies this latter perspective, adopting the view that all persons have the ability to lead in their own way. That is, although each person will use a certain leadership "style" and be faced with their own unique set of leadership challenges, it is a basic premise of the project that everyone has the capacity to learn and apply leadership skills.

The Learning to Lead...Leading to Learn project commenced in 1992 as a collaborative effort on behalf of the University of Minnesota's Institute on Community Integration, Minnesota 4-H Youth Extension Services, St. Paul Public Schools, and the Rum River Special Education Cooperative. Implemented in a multiple phase sequence, one of the key objectives of this demonstration project is to develop and promote the leadership skills of groups of youth with disabilities. By doing so, it is anticipated that the project will address the pervasive problem of the lack of control youth with disabilities exercise over important aspects of their lives by helping them to develop the skills necessary to assume leadership roles in society..

The project was launched by conducting a comprehensive literature review of leadership programs and activities designed for youth, particularly projects that have employed innovative methods to include groups who have been excluded or underrepresented in society. This effort was augmented by conducting extensive data collection activities, both through focus groups and applied survey research. Focus groups were conducted to identify key issues specifically related to the topic of leadership and persons with disabilities. Participants included multiple groups of students with and without disabilities, parents of students with disabilities, general and special educators, community leaders, and adults with disabilities. In addition, two sets of leadership scales were developed and administered to groups of teachers, parents, and students with and without disabilities. Their purpose was twofold: to ascertain the extent and general nature of leadership skills possessed by youth with disabilities, and to determine the degree to which they were given the opportunity to exercise leadership skills in the course of their daily lives.

In addition to these research initiatives, project staff, supported by public school and 4-H staff, engaged in the design and development of a leadership curricula currently being implemented in a total of four demonstration sites in the St. Paul Public Schools and the Rum River Special Education Coöperative. Each demonstration site includes groups of youth with physical disabilities or mild mental retardation along with cohorts without disabilities. Within these groups, youth participated in a series of activities that emphasize important components of leadership. Developed as 18 skill-building activity units, the Learning to Lead... Leading to Learn curriculum covers the following topics:

- What is Leadership?
- Self-Awareness and Self-Esteem
- Individual Differences
- Identifying Ways to Lead
- Communication
- Assertiveness
- Teamwork
- Group Facilitation
- Parliamentary Procedure
- Problem-Solving
- Conflict Resolution
- Advocacy and Self-Advocacy
- Leadership Issues and the Future

A key feature of this curriculum is the development and initiation of an individual leadership plan. In generating this plan, students identify the ways and means through which they will work to achieve objectives in leadership areas for which they have expressed a personal interest or challenge. In support of this effort, students also engage in mentoring

activities with their choice of peers, educators or leaders within the community. Finally, as a means of monitoring individual student progress, a series of objective-based assessments are used for each unit of the curriculum.

Upon completion of the implementation phase, an extensive review will be conducted with group facilitators to assess what aspects of the curriculum need to be changed or modified to ensure a quality product. This will be accomplished through individual and group interviews with participants and by reviewing notes and other documentation maintained by facilitators. Once the information has been compiled, the curriculum will undergo final revision and be available for distribution to special educators across the country in late 1995.

Michael N. Sharpe is Coordinator with the Learning to Lead...Leading to Learn project at the Institute on Community Integration, University of Minnesota, Minneapolis. For more information about the project and curriculum, contact him at (612) 624-0096. The project is supported by a grant from the U.S. Department of Education, Office of Special Education Programs.

Choosing to Lead: Theresa Maefield

Theresa is an excellent example of the highly motivated youth participating in the Learning to Lead...Leading to Learn project. A 19-year-old student who is in the 12th grade, Theresa is a vivacious young woman who likes to interact with others. When asked to describe herself, she says that she is a "nice" person who has a sense of humor that makes people laugh, and that she has set many goals for herself. Along with math and English classes, she is involved in a special education program through which she has the opportunity to engage in job training and work activities within the community. Participation in this program supports Theresa in working up to 35 hours a week at a supermarket to earn money and help maintain a household with her mother, grandmother, two brothers, and a sister.

Despite her highly industrious nature and commitment to her job, Theresa made a decision to forego an afternoon of paid work once a week in order to participate in the Learning to Lead...Leading to Learn project. She says that she likes participating in the project because she gets an opportunity to interact with other students, share her opinions on the subject of leadership, and learn from others as well. To Theresa, being a leader means helping others, knowing what you want in life, setting goals for the future, and speaking up for yourself whenever necessary. While she feels she is a leader at times, she says that there are times when she does not lead because "even persons with stronger leadership skills can't be expected to be leaders all of the time."

Theresa sees herself as "a little bit of a leader" and is interested in learning and using new leadership skills in the future. Aside from acquiring leadership skills, participating in the project has helped her to learn more about herself as a person and as a potential leader. While she feels it is more challenging to take on the role of a leader in new situations or with new groups, she always tries to give it her best effort. Along with the weekly sessions that cover some aspect of leadership development, Theresa says that she enjoys the opportunity to work with a mentor and see how leadership skills can be applied in the community. Because she feels she has grown as a result of her experiences in the project, Theresa has expressed an interest in continuing to be involved in leadership activities in the future.

When asked about her plans for the future, Theresa says that she wants to continue her education beyond high school and pursue a career in the area of child care. She has worked with young children in such settings as youth camps and babysitting, and believes she can use these skills in a career. She is currently exploring academic programs that are available at local technical colleges.

Theresa Maefield is a senior at Highland Senior High School in St. Paul, Minnesota. She was interviewed for this article by Louise Tetu of the Learning to Lead...Leading to Learn project.

Students in Community Leadership

by Julie Schreifels

In Minnesota, Community Transition Interagency Committees (CTICs) have been established by state mandate to improve local services and supports for students with disabilities who are in transition from high school to adult community living. Across the state, over 70 CTICs comprised of school staff, business people, community services personnel, parents, and students with disabilities provide leadership in meeting the transition-related needs of youth and young adults ages 14-21.

The Goodhue County Education District - Community Transition Interagency Committee (GCED-CTIC) focuses on students in four southeast Minnesota school districts. Among its activities are a futures planning workshop and course to assist students in planning and implementing future adult goals in the five areas of transition: home living, recreation and leisure, community participation, jobs and job training, and post-secondary education and training. In the process of implementing this training, four subcommittees were formed: futures planning, transition fair, parent involvement, and student involvement. The student involvement committee noted that input from local high school students with disabilities would be vital to successfully fulfilling the CTIC's mission to help students with various disabilities become informed and productive adult citizens. Not only can students tell us what they need, but also how to present information in a way that would be interesting to them and their peers.

Various ideas for getting students to participate on the CTIC were initially discussed. These included starting a student group similar to the CTIC, having parent members encourage their children to join the CTIC, and having teachers mentor student members. The idea that sounded most workable was to have each teacher bring an interested student or two to the meetings. The teachers would become mentors for the students, helping them become familiar with the committee process.

As one of the teacher members, I asked my futures planning class for volunteers. Three students volunteered to attend a CTIC meeting and check-out this group of adults. We discussed what the committee does and the basics of being part of such a group. After looking over the agenda together the students – Matt, Jenny, Tricia – and I were off to the first CTIC meeting of the year.

When introduced, the students were met with many warm greetings. During the meeting everyone was initiated with a presentation entitled "What is a CTIC?" The committee then decided on three subcommittees for the year: transition fair, futures planning, and parent involvement. Jenny volunteered for the futures planning committee. Matt and Tricia joined the transition fair committee.

After everyone got into their respective committees, I remember hearing various CTIC members asking the students for their input. For example, the transition fair committee asked, "How long should the break-out sessions at the transition fair be?" Matt and Tricia felt that a half-hour would be long enough, and the committee took their advice. In addition, Matt and Tricia took charge of designing the flyer and banners for the fair and of the CTIC booth, with assistance from other members.

Jenny had participated in the first futures planning

CTIC, continued on page 27

A Student's View of Leadership: Matt Schmolke

I think a leader is someone who stands out in the community. A leader helps people or volunteers in their community. Leaders are different from people who are not leaders because they are more well-known in the community. Leaders are usually in charge of the groups they are involved with.

My leadership roles include student council, Students Against Drunk Driving (SADD), and I am a student representative on the Goodhue County Education District Community Transition Interagency Committee (GCED-CTIC). I am also in a program called Athletes for Outreach for Special Olympics. I volunteer a lot on student council and I helped a lot with the GCED-CTICs transition fair. I made most of the banners and signs on my time. I enjoy speaking up at meetings and try to take charge some of the time. I was a member of the team that put on teamwork inservices in this region. I hope to do more inservices in the future; this experience has helped me be able to stand up and talk in front of more people.

Putting on these workshops has helped me learn how to start off a meeting for the student council or get anything else going. I am more sure of myself when I start a Special Olympics event like our track and field practices. It has helped me out with pretty much anything I do.

I think I would like to pretty much take on whatever I can in the future or whatever I can handle or take on in life. But the thing I would really like to some day take on is my own business or something like that.

Matt Schmolke is a Junior at Red Wing Central High School in Red Wing, Minnesota.

Leading by Serving: *Maryland Student Service Alliance*

by Cathy L. Brill

The Maryland Student Service Alliance engages students with disabilities in service learning – as providers, rather than receivers, of service. Throughout their lives, children who are "different", who have "special needs," are usually recipients of service from others. Getting youth with disabilities involved in service learning turns the tables. Service learning involves them in their communities. They learn about issues and needs, take action to meet those needs, and reflect on their experience. It's a powerful teaching and learning tool that has great potential to prepare community leaders.

Despite the inclusion efforts in schools across the country, isolation from nondisabled peers and the community at large is an ongoing problem for young people with disabilities. By planning service learning projects that include nondisabled peers, students with disabilities are more fully integrated into their schools and communities. As others in the school observe the contributions made by the students with disabilities, they grow to respect the unique capabilities of the group. Rather than seeing the students as a drain on resources, others come to see them as assets to the school. As people with disabilities speak out to demand their rights, they can strengthen their case by making a contribution to their communities and taking on the responsibilities of citizenship through service.

The Maryland Student Service Alliance's special education initiative began with the hiring of a specialist in 1991 who provided ongoing technical assistance to teachers and schools. The specialist worked with a group of special education teachers to develop a curriculum guide and teacher training agendas, and provided on-site assistance in making contacts, finding service sites, planning programs, and dealing with the media. Pilot programs were started in half of Maryland's school districts. In July, 1992, the Maryland State Board of Education passed a service learning graduation requirement for all students, including those receiving special education services. The Alliance worked with school districts across the state to ensure that provisions were made for students with disabilities to meet the new requirement.

Teachers in Maryland have used several approaches to make service learning the engine that drives inclusion at their schools. Some engage students with and without disabilities in projects together, involving general and special educators from the start. Another approach is reverse inclusion; special education teachers start a project with their students, and then include students without disabilities as fellow participants. In this way, the students with disabilities become the leaders. Still other teachers create a program that is so attractive that regular education staff and students want to be involved with them and their students. Teachers also use partial participation in service projects to help drive inclusion; they pair their students with a class of students without disabilities who have complementary skills.

So what do students actually do through the Alliance? The following are some of the service learning projects that are taking place:

- Students with mental mild retardation at a high school serve once a week at a local hospital in various departments – front desk, ob/gyn, cardiology, housekeeping, and patient escort. Students go to the hospital as a group with their teacher, then go to their assigned departments. They keep journals of their impressions and experiences and read books about illness and health care.
- Middle school students with moderate to severe disabilities work on environmental projects with their nondisabled peers. They plant marsh grass to prevent beach erosion, paint storm drains with "Don't Dump" messages, and plant trees. Students learn to work together while they learn science lessons and help protect natural resources. Reflection includes discussion and journals.
- High school students with severe to profound mental retardation work with regular education students to create a disability awareness slide show to be presented to all classes in their school.
- Students with moderate to profound mental retardation at a special school help manage a clothing program for needy families. A group of students travels to the clothing site two times a month to sort and hang clothing and bring back items needing cleaning or repair. Other students at the school clean and mend the clothes in the school. The students have discussed the needs of low-income families. For some of the more profoundly involved students, skills learned are basic and functional, such as sorting pants and shirts, and deciding what needs cleaning.

In a survey of middle and high school special educators conducted in 1992, teachers cited improved self-esteem, more consistent completion of assignments, greater sensitivity to others, improved social skills, and improved relationships with nondisabled peers as outcomes of service involvement for students with disabilities. Through service learning, students gain self-esteem and functional skills in the areas of teamwork and decision-making. They take on leadership roles as they carry out projects, and their status rises within the school and community.

Cathy L. Brill is a staff member with Maryland Student Service Alliance. For more information on the Alliance, contact Maggie O'Neill at (410) 767-0358.

Empowerment Through Leadership Education

by Stephanie Agresta, Betty Aune, and Gene Chelberg

Despite legislation providing full access to higher education for individuals with disabilities, few efforts have been made to prepare youth and young adults with disabilities to function effectively in leadership roles. The University of Minnesota's Project LEEDS (Leadership Education to Empower Disabled Students) is currently in its second year of working to change this state of affairs by developing leadership potential and opportunities for students with disabilities in American colleges and universities.

Traditionally, disability has been viewed as a deficit that resides within the individual. The solution to disability-related problems, in that model, is to "fix" the individual. As a result, students with disabilities have generally been thought of as *recipients* of services, not as *providers* of services or as *leaders*. A new paradigm of disability views disability as a difference. Disability-related problems in this paradigm do not reside within the individual, but rather occur when the person interacts with society. In this view, society needs fixing, not the individual (Gill 1987, 1992; Hahn 1985). The environment must be adapted to accommodate a wide range of differences in our society. Viewing disability from this perspective, it is natural to think of persons with disabilities as potential leaders, ideally suited to guide the way in making our environment accessible to all.

> ...it is natural to think of persons with disabilities as potential leaders, ideally suited to guide the way in making our environment accessible to all individuals.

Project LEEDS is uniquely positioned to fill a gap in leadership education, a field that has not developed approaches uniquely designed for students with disabilities. The project's theoretical model of leadership is a synthesis of competing theories of leadership, with the important additional perspective of disability culture. Students are empowered to envision themselves as leaders and as members of alliances between students and staff with and without disabilities. Further, students gain multiple perspectives on organizations and working within complex systems.

Last August at the University of Minnesota, Project LEEDS hosted the first National Institute on Disability and Leadership. Sixteen student/staff teams from colleges and universities around the nation gathered to explore issues of leadership and identity formation, the nature of power and disability, tools for community building, organizational theory, and the synergy of alliance. One tangible result of the Institute was each team's development of a campus action plan to improve the campus climate for students with disabilities at their home schools. While working to improve the campus climate, Project LEEDS participants have had the opportunity to put leadership skills and theory into practice. The knowledge gained and skills developed through this work will not only make lasting changes in the environments in which the participants live and study, but more importantly, will create a cadre of leaders with disabilities to meet the challenges and opportunities of full societal integration of people with disabilities.

Currently, 1994 institute participants are implementing their campus action plans at their colleges/universities. Incorporating ideas on leadership and disability identity, students and student affairs professionals have undertaken a variety of activities on campuses across the nation. At the University of Texas-Austin, for example, the LEEDS team has developed and implemented a test-taking accommodation policy, as well as sponsored a campus-wide discussion series focusing on combating attitudinal barriers faced by students with disabilities. In Cincinnati, Ohio, at Xavier University, the student/staff team worked with campus stakeholders to negotiate a $20,000 renovation project to establish a centrally located campus office strictly for the Learning Assistance Program. Additionally, team members have worked with students with disabilities on campus to initiate a peer tutor training program. At Sonoma State University in California, team members have created the Disabled Student Organization for their university, as well as consulted with faculty and students in establishing a Disability Studies minor in the curriculum.

> Students are empowered to envision themselves as leaders and as members of alliances between students and staff with and without disabilities.

The LEEDS model promotes the collaboration of students and staff as change agents at their home institutions, and uses this alliance to maximize the personal and professional resources of participants. Professional staff have a unique role to play in effecting institutional change. As leaders themselves, student affairs professionals provide expertise on campus environments and power structures, while also serving as role models and partners to achieve the goals established by each team. Students gain the opportunity to build their leadership skills while also working with campus allies to improve campus life for students with disabilities.

The work of Project LEEDS staff and participants

continues. The second National Institute on Disability and Leadership was held in Minneapolis, June 21-27, 1995. Fourteen student/staff teams representing colleges and universities across the U.S. and Canada participated; they have now returned to their home campuses energized and prepared to implement campus action plans. With technical assistance from project staff, last year's participants have begun planning three regional conferences on disability and leadership hosted by Darton College (Albany, Georgia), Moorhead State University (Moorhead, Minnesota), and San Francisco State University to be held in late summer and early fall of 1995. LEEDS staff will also conduct a pre-conference workshop at the AHEAD National Conference, San Jose, California in July, 1995; this workshop will be highly interactive and feature components of the Institute on Disability and Leadership Curriculum. Finally, beginning in the fall of 1995, Project LEEDS will make available at cost its *Disability and Leadership Curriculum Manual* for use in training and development.

Stephanie Agresta is a Graduate Assistant, Betty Aune is Project Director, and Gene Chelberg is Project Coordinator with Project LEEDS, University of Minnesota, Minneapolis. For more information on Project LEEDS, contact Betty at (612) 624-6884. The project is funded by the Dwight D. Eisenhower Leadership Development Program.

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The Project LEEDS Experience: Ivana Kirola

A leader is someone who believes in their cause and wants to encourage other people to stand up for their beliefs, in turn becoming leaders themselves. As a participant in Project LEEDS, I developed my understanding of leadership and disability in ways that have helped me to help others become leaders, as well as assisted me in working with others to improve the campus environment for disabled students.

At San Francisco State University (SFSU) where I am currently enrolled as a sophomore, I've had experiences where I've talked to people who want to bring about changes in the university system. They keep mentioning issues while they talk to me, but are not focused. I've found that Project LEEDS helped me to develop the ability to stay focused on one issue rather than the myriad of issues that so often exist for people with disabilities. Project LEEDS, by hosting the 1994 National Institute on Disability and Leadership, also brought me into contact with other leaders at the national level. Most importantly, the project assisted me with answering the number one question on my mind and I think the minds of others: How does one link the goals of the disabled community and the community at large? I learned that there is not one empirical way to go about answering this question, but that there are many ways. The key to leadership in many cases is allowing development.

Leadership, as with anything else, has its own set of challenges. Acting as a mediator to bring people together on issues is often very demanding because everyone has their own set of ideas and values that they feel are important. Another big issue that comes to my mind is time. Currently, I am the president of the Organization of Students With Disabilities (OSD) at SFSU. I also serve as a member of the search committee to find a new director for the disability services program on campus. I try to prioritize things according to their importance.

Another tactic for dealing with time demands is delegating power to other leaders or people who are in the development stage of leadership. I think that there is a common misconception in society of leaders being Ms. or Mr. Know It All. This is not true. Knowing who in the community to approach for specialized knowledge is a key aspect of leadership, and one which is required in order to manage one's time in the best way.

Getting involved in disability issues transformed me from one of the few shy mainstreamed kids in my school district to my leadership role on SFSU campus. In the future, I'd like to take a leadership role of advocating involvement in the local community on disability issues. I'd also like to work on advocating the independent living movement philosophy in the U.S. and other countries.

Ivana Kirola, a sophomore at San Francisco State University, is a 1994 Project LEEDS participant and attended the first National Institute on Disability and Leadership.

Remembering with Dignity: Leadership Through Activism

by Jerry Smith

Behind the old brick dormitory buildings of the regional treatment center in Faribault, Minnesota, stands a tall, white cross. Before the cross, just below ground level, lay flat steel plates stamped with a number. Laid in a grid, the hundreds of markers correspond to a chart, stored somewhere in the archives of the institution, of the people buried here over the past 120 years. Not unique to Faribault, tens of thousands of people who lived and died in our nation's institutions were buried anonymously. Kept hidden from society, these citizens were denied one last act of dignity: to have their names on their gravemarkers.

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In September of 1994, members of the self-advocacy organization Advocating Change Together (ACT), along with members of the Minnesota Association of Persons with Severe Handicaps (MNASH), local People First chapters, the Minnesota Disability Law Center, and the community at large met to discuss the issue of placing markers on the graves on the many individuals with disabilities who lived and died in our state's regional treatment centers. As a matter of respect for institution residents, and for the dignity of those who have been fortunate enough to move out into the community, the group began a project called Remembering With Dignity to publicly recognize our forgotten citizens in state institutions and allow a healing process to begin for family and friends. With the planned closing of Minnesota's regional treatment centers within this decade, the group felt that a respectful acknowledgment of those who lived within our institutions would serve as a closure to our history of institutionalizing persons with developmental disabilities, and as a poignant reminder of how easy it is to separate ourselves from those we see as different.

Since the first meeting of Remembering With Dignity, participants – particularly those who have lived in institutions – have been passionate about the need for respectful gravemarkers at Minnesota's institutions. "My husband, Dean, lived in four institutions," said Gloria Steinbring, "Owatonna, Cambridge, Fergus Falls, and Faribault. When he died, I made sure he wasn't buried at the institution. His gravesite has his name on it, with the year he was born and the year he died. I'll be buried next to him." Many other participants in this group, including individuals who live in group homes and high-rises, and younger self-advocates who have never seen the inside of a regional treatment center, identify with this issue because they understand this injustice. "Many of us have been treated like a number all our lives by social workers," said Heidi Mhyre, a young self-advocate. "To be buried as a number isn't right; they should at least be given their name back."

Unlike many programs aimed at developing the individual leadership skills of persons with disabilities, Remembering With Dignity is developing leadership through grassroots organizing around an issue of common concern; people are drawn to participate through a feeling of injustice, and many assume leadership roles because they are acutely aware that no one knows better than they what it means to live in an institution. Some of the people involved in this group are active in their self-advocacy groups; others have never spoken out publicly. As advisors to Remembering With Dignity, members of ACT and MNASH have worked with the larger group in defining goals and strategies. Members of the group decided that their primary goal would be to place names and dates on the gravesites, beginning with one institution. As the Faribault regional treatment center is very quickly being converted to a corrections facility, the group decided to begin there, working with the local community to preserve the history of the institution as told by those who lived there. "This is our history," said Gloria Steinbring. "It belongs to us. We need to preserve it so people will know how we've lived and what we've been through."

While Remembering With Dignity has the support of advisors and professionals, its work and direction have been the responsibility of self-advocates. They have formed working groups, dividing the project into three areas: placing names on the gravesites, collecting oral histories of life in institutions, and increasing public awareness of the historical role of institutions for people with disabilities. As a first step toward placing names on the gravesites at Faribault, participants with an interest in community organizing have set the goal of identifying the names and dates of birth and death of the persons buried at the site. Having identified a committed group of self-advocates and community members in Faribault, the Twin Cities group will work with them to recruit volunteer support and also identify potential opposition to

this project. At this stage, they have encountered no opposition; administrators at Faribault have been cooperative, expressing interest in having their history preserved. Community groups, including the Jaycees, have offered their assistance in raising funds for the markers.

The process of collecting oral histories is providing opportunities for individuals to share their stories with others who have lived in institutions, while developing presentation skills through conducting interviews. Upon collecting the oral histories, this group will explore ways to use these stories in a lasting public exhibit on lives lived in institutions. Cliff Poetz, of People First Central in Minneapolis, met with the Minnesota Historical Society to explore using oral histories as part of an exhibit on institutions. Group members – many of whom do not consider themselves leaders – are able to draw from their unique experiences with institutions and use them as a catalyst for recruiting new interviewees. Uncovering the stories of those who have lived in institutions is an act of historical and social significance; helping former institution residents understand their history and share in this process of healing is an act of leadership.

To increase public awareness of the past and present roles of institutions, group members are developing strategies for working with local media in communicating the goals of Remembering With Dignity and telling the first-person stories of life in institutions. The first task the public awareness working group accomplished was writing a one-line mission statement: "Honoring those who lived and died in Minnesota's state institutions by telling their stories and preserving our history." Self-advocates Barb Eaton, John Daggy, and Gloria Steinbring were chosen to serve as public speakers and contacts for the media. John, in his mid-60s, had never heard of self-advocacy before this issue. After learning of the effort to honor those who lived in institutions, John came forward and told his story of being committed to Faribault as a child. Over the past months he has visited the county courthouse repeatedly, looking for information on people he knew while at Faribault. Members of the group who are not as comfortable speaking publicly are working with volunteers in assembling a media kit containing photos of the cemeteries, a mission statement, the project goals, and information on how people can join this process. This group is also videotaping the organizing process, and will use this footage along with the oral histories to create a documentary program for public viewing.

> Remembering With Dignity is developing leadership through grassroots organizing... many [people] assume leadership roles because they are acutely aware that no one knows better than they what it means to live in an institution.

Remembering with Dignity is also keeping a high-profile among legislators and other disability and social change organizations. Minnesota State Senator Linda Berglin, a strong supporter of disability rights, has asked the group to help write a resolution asking the State of Minnesota to formally apologize for institutionalizing persons with developmental disabilities. Steve Burnley, a man who lived in Cambridge state hospital from age 11 to 18, looked back on his years in the institution: "You know, no one ever said to me 'I'm sorry.' No one ever apologized for locking me up. I'd just like someone to apologize."

The Remembering with Dignity project is one of several similar efforts that have taken place across the country in recent years. Pennsylvania's former First Lady, Ginny Thornburgh, led an initiative to memorialize persons buried in Pennsylvania's state operated institutions for persons with mental retardation and mental illness by re-dedicating the cemeteries, placing new headstones on the graves bearing the deceased person's name and dates of birth and death. More recently, David Leshtz and Barbara Smith at the University of Iowa developed a program to record and tell the stories of people who lived in Iowa's institutions. Leshtz and Smith recruited members from the community – students, teachers, social workers, amateur historians, family members and friends – to interview former residents of Glenwood State Hospital School and Woodward State Hospital School. University of Iowa theatre graduate Todd Ristau used the oral histories to create the play, *Immigrants From Within*.

There are still 70,000 people with developmental disabilities living in public institutions, thousands more in private institutions, and hundreds who are admitted every year. The stigma of being labeled "mentally retarded" and removed from mainstream society has been felt by many Remembering With Dignity participants. The insult of thousands of anonymous gravesites is an enduring metaphor for our perceptions of disability. With the initiative and effort of leaders with disabilities such as those involved with Remembering with Dignity, people who lived and died in institutions are being remembered, and those who have survived the institutions are being given the opportunity to tell their stories, ensuring that this part of our history is not forgotten.

Jerry Smith is Communications Director with Advocating Change Together in St. Paul, Minnesota. For more information on Remembering with Dignity contact Walter Rupp at (612) 641-0297.

Resources

The following resources are related to the development of skills, attitudes, and opportunities necessary to support the leadership potential of individuals with developmental disabilities. Please contact the distributors listed for information about ordering the materials and for costs.

• **Self-Determination for Youth with Disabilities: A Family Education Curriculum** (1994). A 15-module curriculum developed to teach families skills for supporting the exercise of self-determination by their transition-age member with a disability. It is designed to be presented by teachers, community agency personnel, or other facilitators in a series of two-hour sessions. Available from the Publications Office, Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Dr. SE, Minneapolis, MN 55455 • (612) 624-4512.

• **Leadership for Empowerment Program: Serving Junior High Youth With and Without Developmental Disabilities** (1994). A curriculum that provides the tools for a youth development professional to begin an inclusive service leadership group or make an existing group inclusive. The manual addresses group formation, meaningful service, and reflection. Includes a videotape, program manual, posters, and resource brochures. Available from Polly Harrison, Ridgedale YMCA, 12301 Ridgedale Dr., Minnetonka, MN 55305 • (612) 544-7708.

• **Not Another Board Meeting: Guides to Building Inclusive Decision-Making Groups**. Three guides that raise questions about the supports group members need to make decision-making more meaningful for all. This tool brings self-advocates, support persons, and group members together to talk about their group's purpose. Available from the Oregon Developmental Disabilities Council, 540 25th Place NE, Salem, OR 97301 • (503) 945-9941.

• **People First: Leadership Training Manual (1988).** A manual written to help self-advocates learn to organize and to stand-up for their rights. It defines self-advocacy and leadership; describes how People First and other groups can help self-advocates; and talks about organizing, strengthening, and advertising a group, and choosing an advisor. Available from National People First Project, Kinsmen Building, 4700 Keele St., Downsview, Ontario M3J 1P3 Canada • (416) 661-9611.

• **Taking Charge** (1993). A leadership training project designed for groups of 10-12 people, about 14 hours in length. It combines personal development exercises with skill building in small and large group process, speaking, writing, planning, and goal setting. Available from Heritage Centers of Buffalo, 101 Oak St., Buffalo, NY 14203 • (716) 856-4201.

• **Voices That Count: Making It Happen (1993).** A presenter's guide written to help self-advocates learn the skills necessary to speak to groups about leadership roles and opportunities. Speakers using the guide will give boards and committees ideas on how they might recruit and build partnerships with self-advocates. There is an audiotape of the guide to assist users, and there is also a videotape to be used as part of the presentation to boards. Available from Cincinnati Center for Developmental Disorders (UAP), 3300 Elland Ave., Cincinnati, OH 45229 • (513) 559-4639 / 559-4626 (TDD).

• **No More B.S.: A Realistic Survival Guide for Disability Rights Activists** (1992). A book addressing self-advocacy as part of the broader disability rights movement. It provides information, resources, and motivation about organizing to make change in the lives of people with disabilities. Available from People First of Washington, P.O. Box 648, Clarkston, WA 99403 • (509) 758-1123.

• **Spreading the Word** (1993). A booklet on self-advocacy based on what Speaking for Ourselves has learned over the past 10 years. It is written for members of self-advocacy groups to use together. Topics covered include where the group started, who the members are, principles for which the group stands, how the group is organized, definition of a chapter, what happens in the chapter, how members are involved, and the advisor's role. Available from Speaking for Ourselves, One Plymouth Meeting, Suite 530, Plymouth Meeting, PA 19462 • (610) 825-4592.

• **A Call to Action: The Roles of People with Mental Retardation in Leadership** (1992). A handbook outlining the proceedings from the leadership forum held during the Arc's 1991 national convention. It also discusses barriers and strategies to supporting leadership of people with mental retardation. Available from Arc National Headquarters, P.O. Box 1047, Arlington, TX 76010 • (817) 261-6003.

• **Self-Advocacy: Print and Media Resources** (1995). A guidebook listing nearly 150 publications and media materials about self-advocacy. Topics include building self-advocacy groups, financial issues, health and medical concerns, legal rights, self-advocacy skills, the Americans with Disabilities Act, and Personal Futures Planning. Available from Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Dr. SE, Minneapolis, MN 55455 • (612) 624-4512.

Eaton, continued from page 1

called Remembering with Dignity (see story on page 24). "I got involved with Remembering with Dignity because I've been there. I told my own story and now I want to help others do the same. I'd want someone to do this for me."

Barb brings her experience and a great deal of sensitivity to the organizing sessions for Remembering with Dignity. Her leadership ability shows through in her comments and suggestions about the importance of preserving and telling the life stories of people with disabilities. She understands the importance of people with disabilities themselves owning and taking on the responsibility to document their history. In a recent organizing session, Barb worked in a small group to create a statement that describes the Remembering with Dignity mission: "Honoring those who have lived and died in Minnesota's state institutions by telling their stories and preserving our history." Barb says that she is proud of this statement and that she feels that her own experiences were helpful in writing it.

Barb Eaton didn't learn to be a leader by participating in a program or project to develop such skills. Her leadership skills were developed by doing. She was motivated by an issue and the desire to make change in her own life and the lives of others. "I think a leader is someone that knows what they want and they have goals and they just do it. Leaders have gumption." She says that she will continue to work on issues of concern to people with disabilities long into the future and that such work is her job. This quote from T.S. Eliot, which opens the video documentary about Barb, expresses her belief that often the effort is as important, if not more so, than the outcome: "There is only the fight to recover what has been lost, And found, and lost again... But perhaps neither gain nor loss, for us there is only the trying." Barb agrees. "I will work with groups like the Remembering with Dignity group or all alone. It depends. If something needs to be done to help people or make things better, I'll work to do it. I just want to get things done."

Walter Rupp is the Community Organizer for the St. Paul, Minnesota, self-advocacy group, Advocating Change Together, which is the home of Remembering with Dignity.

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themselves as leaders, it is likely that most will live their lives without ever reaching their potential to contribute to the community in a leadership role. If current trends continue and persons with disabilities are not provided with opportunities to acquire, practice, and refine those capacities that will allow them to effectively function within leadership positions, a void will be created that may take years to fill. The lack of opportunity within this area has already created a situation in which many creative, highly skilled individuals are never able to use their talents to improve the quality of their own lives as well as those of others.

What can be done to facilitate persons with disabilities filling leadership roles? To train the leaders of tomorrow, leadership instruction must be provided, not only to adults, but to children and youth as well. Along with opportunities to acquire basic skills within this area, persons with disabilities must also be given the chance to serve in leadership capacities within society at large. Efforts must also be made to insure that color, gender, economic background, and the presence of a disability do not preclude an individual's functioning in a leadership role. For all persons, leadership development starts with full participation in school, work, and community life and the development of a sense of self-determination. It culminates as individuals move themselves and subsequently others from dependence to interdependence, from being spectators to leaders.

Brian Abery is Coordinator of School Age Services and Michael N. Sharpe is a project coordinator, both with the Institute on Community Integration, University of Minnesota, Minneapolis. Brian may be reached at (612) 625-5592 and Mike at (612) 624-0096.

CTIC, continued from page 20

workshop in April of 1994. As a member of this year's futures planning committee, she shared her insights on how the workshops could be improved and the parts that should remain the same. The CTIC had become involved in a grant to pilot a new IEP form, the Minnesota Individual Family Plan of Interagency Support, and the futures planning committee spearheaded the implementation of this new project. The new committee's goal was to get at least 10 plans written in Goodhue County by June of 1995. It was decided to conduct an inservice training on the new plan for teams interested in the concept of one interagency service plan for students with disabilities and their families. Jenny and her family volunteered for the starring roles in the videotape prepared for the inservice training.

At each monthly meeting, I watched the three students become more and more confident in giving their input. They have become truly valued members of the GCED - CTIC, so valuable, in fact, that we have asked them to return next year. They all agreed to continue their roles on the CTIC, even Jenny, who will graduate in June. We hope that they will become the mentors for future student leaders.

Julie Schreifels is a member of the GCED-CTIC, and a teacher at Red Wing Central High School, Red Wing, Minnesota. For more information on student involvement in Community Transition Interagency Committees, contact Julie at (612) 388-7181.

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